

ETHICS OF CONDUCTING RESEARCH IN CRISIS SETTINGS: HOW DOES FLINT MEASURE UP?

“Ethics & humanitarian research: generating evidence ethically”

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COMMON CHARACTERISTICS

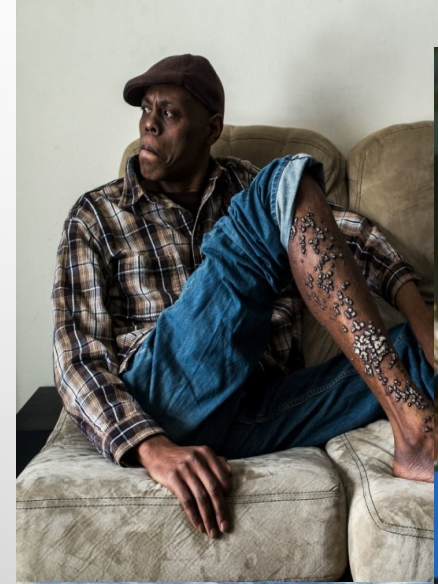
- WHAT DO MOST CRISIS ENVIRONMENTS HAVE IN COMMON?
 - Extreme horror/panic/terror/desperation
 - fear of loss of life and property
 - food shortage/extreme starvation
 - uncertainty, acute insecurity (e.g., violent crimes)
 - unhealthy environment (e.g., water and air pollution)
 - widespread illness (e.g., cholera, PTSD).

DOES CRISIS PLACEMENT MATTER?

What
about gun
Violence?

Ethiopia

Paradise, CA



Internally Displaced People in Flint?



Kearsley Park
IDP Site



PLACISM?

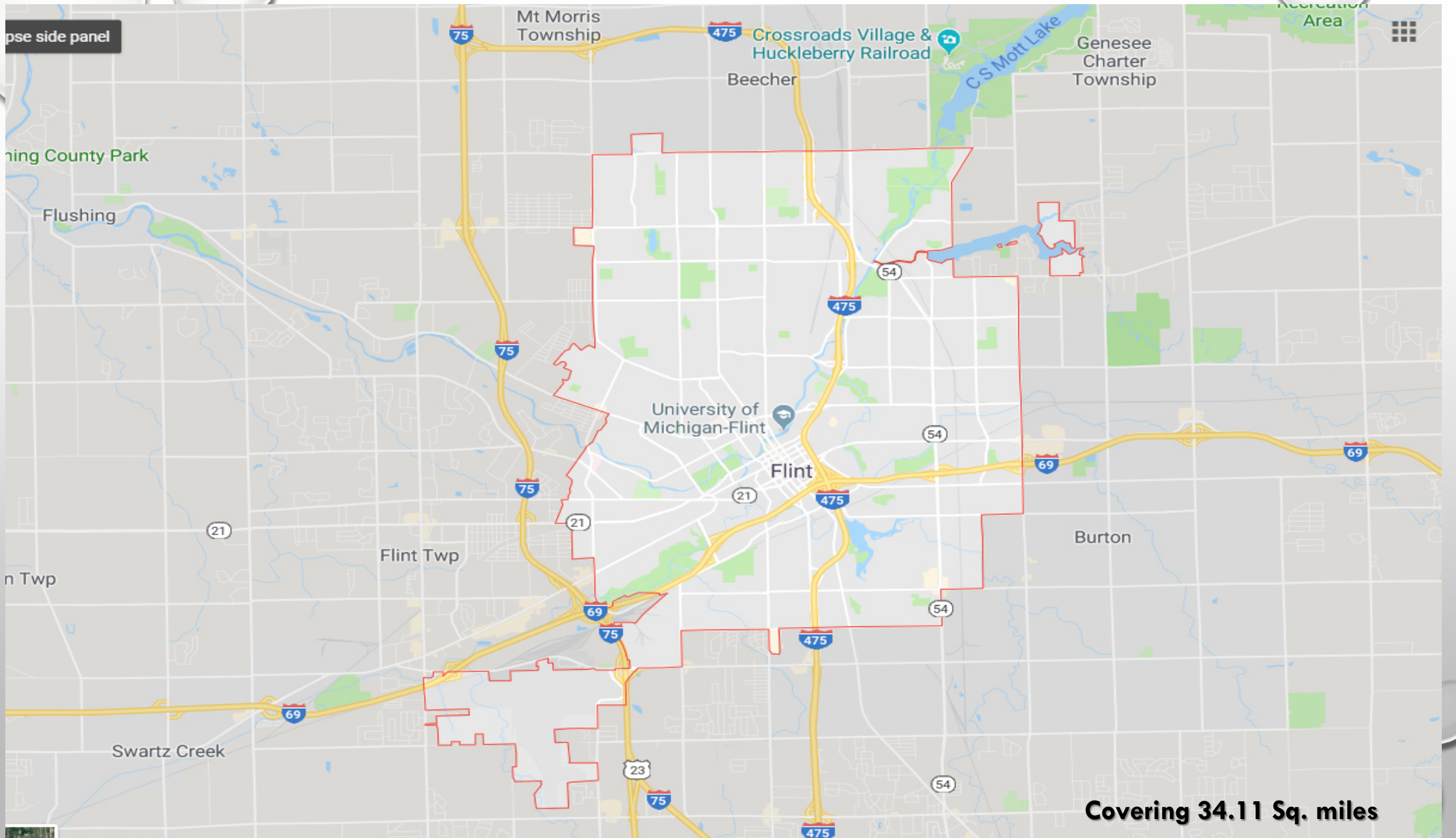
- IT'S A NO BRAINER: humans respond the same in crises or conflict environments
- Fleeing cross-border refugees Vs internally displaced refugees
- Caravan of migrants at the U.S. southern border Vs victims of Hurricane Katrina & Maria, 9/11, etc.
- Disease-stricken people in parts of Africa Vs PTSD U.S. Inner City populations.

FALSE ASSUMPTION?

- It Happens “there” Not “here”
- Assumption that belies daunting ethical issues confronting researchers on both sides.
- Research has found that the instability of conflict-affected areas, and the heightened vulnerability of populations caught in conflict and/or emergency situations, call for careful consideration of the research methods employed, the levels of evidence sought, and ethical requirements, such as the harm-benefit ratio for potential research participants.

FLINT SCENARIO

- “The Vehicle City” is a predominantly black industrial hub 75 miles north of Detroit “The Motor City.”
- 36.2 percent of its current 93,000 residents living below the poverty level
 - Down from a population peak of about 205, 000 in 2009
- Blacks make up 18.4 percent of those living in poverty
- Michigan’s poverty rate was at 16.2 percent
- Listed as one of the most dangerous cities in America
 - It has zip codes with average life expectancy under 65
- Violence, lack of nutrition, unsafe places to play = toxic stresses
- Repetitive stress and trauma impacts entire life course



Covering 34.11 Sq. miles

2014 WATER CRISIS

- Governor-appointed emergency manager (EM) changed Flint's water source from Lake Huron to the Flint River, in April 2014
- EMs were charged with protecting the welfare of citizens with a focus on fiscal "belt-tightening" with no consideration for health risks to residents
- Although required by law in water systems serving more than 50,000 residents, anticorrosive chemicals were not added to the water supply due to cost (less than \$150 a day)
- These decisions resulted in damage to public health from elevated lead levels and *Legionella* in Flint's water as well as over \$100 million in Flint water infrastructure damage
- Government at all levels failed to protect the Flint community the residents were harmed and their trust eroded.



LIVING ON BOTTLED WATER



MSU RESEARCHERS IN FLINT

- First land-grant University model: MSU's 4 health sciences colleges are intimately connected with urban and rural populations of Michigan, as well as with professionals delivering health care to these communities
- At the request of the Flint community, in close collaboration with Flint community organizations
 - CHM expanded its medical school into Flint with community-participatory public health focus
 - Serve public health research and practice needs in the area
 - CHM took unprecedented, community-partnered approach to building its new DPH in Flint
 - Ground zero = belly of the beast.

ISSUES

- Little guidance is available from the mainstream biomedical ethics principles (autonomy, justice, nonmaleficence, beneficence) E.g., how to translate 'beneficence' to the community, cui bono?
- Community-based participatory researchers have argued that the Belmont principles must be re-conceptualized in order to address community-level considerations in ethical reviews

ISSUES CONTD.

- Ethics of community partnership and engagement processes, social justice, and the need to expand the boundaries of ethical reviews to include community-level considerations
- Individuals and non-governmental organizations may face political pressure and barriers to research
 - E.g., Mona Hannah-Attisha's fight with State Government
 - Govt. also refute Virginia Tech research team's report

FLINT MODEL

2009: the Flint Community Based Organization Partners (CBOP), founded the Community Ethics Review Board (CERB)

Services include:

- (1) community ethics reviews and critiques of proposals;
- (2) identifying and assisting in developing a community advisory board for research projects, if needed;
- (3) identifying community partners, research participants, and community research sites;
- (4) suggesting strategies for community engagement
- (5) vetting research ideas
- (6) issuing letters of support for particular projects.

FLINT MODEL CONTD.

- establish a community-level ethical protection entity led by local residents
- members of the CERB are community members with years of experience in research and in ethics committees
- review proposed studies and work with researchers to ensure compliance with human research protections
- ensure community protections and mutual benefits
- continue regular research ethics training for its members to obtain CFR human subjects training certificates from the universities.

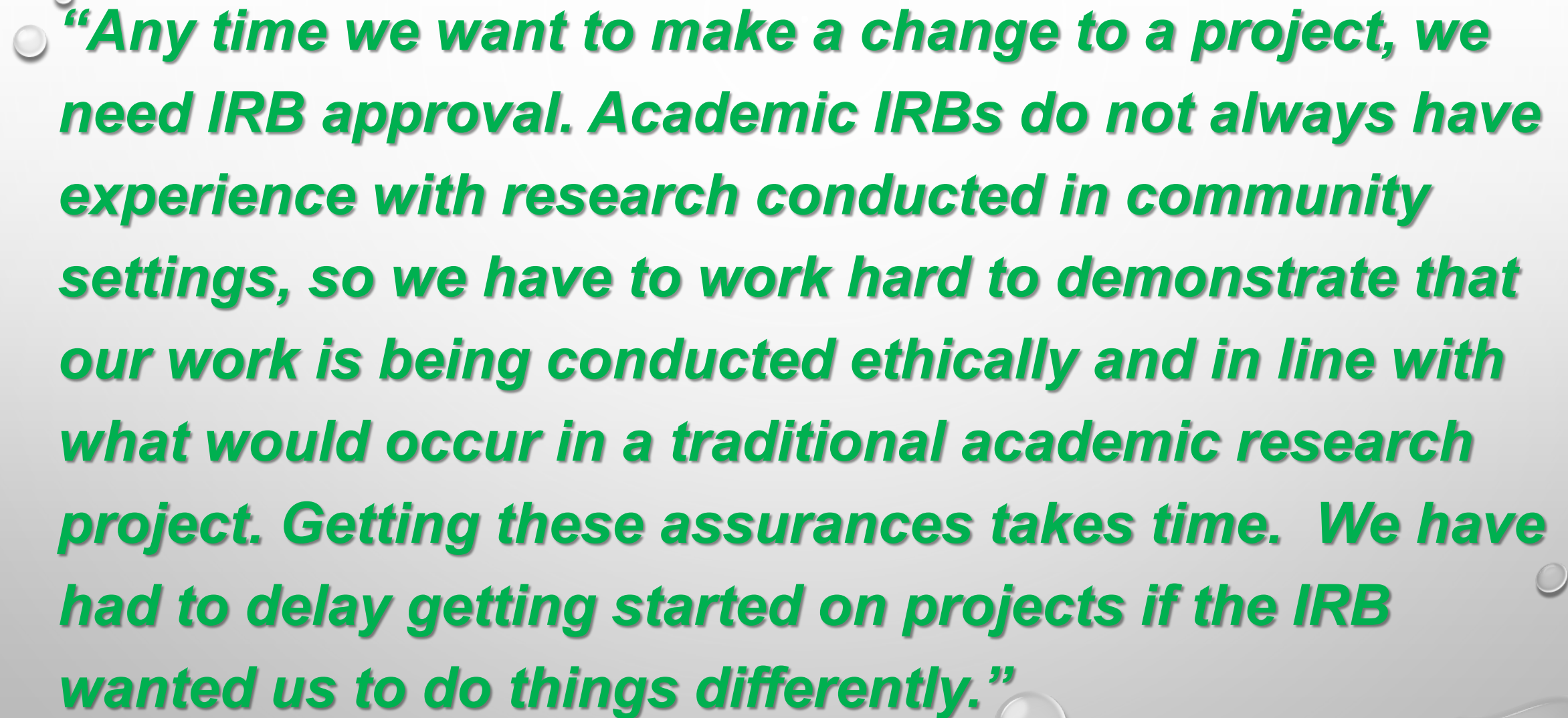
METHODS

Structured face-to-face interviews were conducted to determine the ethical challenges faced by Flint-based researchers (n=7; MSU n=6; U of M-Flint n=1).

- Survey questions included how specifically the conditions of vulnerable population affected research process and methods; pressure to produce results quickly to end the sufferings; harm-benefit ratio considerations; and balancing individual human rights and community participation in research design.

SAMPLE RESPONSES

“I have traveled to 68 different countries around the world (both resource-rich and resource-poor). What I see here in certain parts of Michigan (e.g., Flint, Detroit and even Lansing), is just as bad as many of the war zones I’ve been to.”



“Any time we want to make a change to a project, we need IRB approval. Academic IRBs do not always have experience with research conducted in community settings, so we have to work hard to demonstrate that our work is being conducted ethically and in line with what would occur in a traditional academic research project. Getting these assurances takes time. We have had to delay getting started on projects if the IRB wanted us to do things differently.”

***“For me the ethical heaviness lies in the uncertainty of the potential damage done by the low risk samples that we collect. For instance, the remote possibility of genetic companies accessing our materials for commercial purposes; the insurance companies requiring that their applicants disclose if they ever submitted a sample to DNA labs like 23andMe and Ancestry.com; or the law enforcement accessing DNA samples to investigate people.*”**

Overall, the research conduct on Flint-focused work is highly upbeat.

- Preliminary findings show that,

- Researchers in Flint are just as challenged as any other at conflict/crisis zones
- Presence of CERB has helped to reduce (not erase) problems
- Brighter future awaits –
 - a good measure of this was observed at the

2nd Annual Healthy Flint Research Coordinating Center
RESEARCH SYMPOSIUM, Friday, March 15, 2019

➔ featuring 57 posters, 12 concurrent oral sessions; 2 plenary sessions; and 2 keynote speakers, on wide-ranging topics.

IMPLICATIONS/RECOMMENDATIONS

- The ethics review process should not protect institutional power at the expense of community, but instead reconstruct its review domains to include questions that assess community-level protections, risks, benefits, and issues of social justice and human rights.
- (1) IRBs should partner with local CERBs to conduct a joint-review process
- (2) IRBs should include community members from local CERBs
- (3) IRBs should reroute researchers to local CERBs for protocol review prior to the IRB review and consider the results of the CERB review in their deliberations
- (4) Risks and benefits of research should be justly distributed by engaging the community in the process of identifying and assessing those risks and benefits.

LIMITATIONS

- Current findings are preliminary; sample population needs to increase.
- Further interviews to include community organizations and individuals carrying out interventions and conducting research in Flint.

THANKS FOR LISTENING



March 11, 2019:

World Water Day in Flint was marked by bottled water giveaways.

<https://www.michiganradio.org/post/world-water-day-observance-and-bottled-water-giveaway-scheduled-flint>

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